DOCUMENT RESUME

ED 196 252 EC 131 702

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TITLE Respite Care: "How-To" Manual, State of Colorado.
INSTITUTION Archdiocese of Denver, Colo.
PUB DATE [79]
NOTE 39p.: For related information, see EC 131 701-705.

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Developmental Disabilities; *Family Programs; Policy Formation; *Program Development; *Respite Care

ABSTRACT

The manual considers the development of a respite care program for families of developmentally disabled children. The development of a respite program in the Archdiocese of Denver (CO) is reviewed in terms of policy development, a pilot phase, and problem areas (lack of consumer interest and funding). The rationale for respite care is described and three levels of need qualifying a person or family for service are identified. Appended is the nine page agency survey completed by the Archdiocese of Denver Ministry to the Handicapped regarding its respite care program. (CI)

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RESPITE CARE

"HOW-TO" MANUAL

STATE OF COLORADO

Provided by the Archdiocese of Denver

Written by Cary Carron

2142 South Zenobia Street

Denver, Colorado 80219

(303) 936-7288

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EC131702

This draft represents only the first section of the manual which describes the development of the respite care service.

Content still to be included:

PROGRAM MANAGEMENT

- A. Staff Responsibilities
  (Job Descriptions)
- B. Administrative Policies

COMPONENTS

- I. Community Awareness
  - A. Providers
  - B. Consumers
- II. Provider Training
- III. Screening of Providers
- IV. Intake Process
- V. Matching Consumers with Providers
  - A. Negotiation
    1. Home visit
    2. Fees
  - B. Contract
    1. Time and Place
- VI. Placement
- VII. Follow-up
  - A. Evaluation
  - B. Documentation

IMPLEMENTATION

Respite Care Procedures:

- I. Community Awareness
  - A. Publicity
    1. Brochures
    2. Media
    3. Presentations
  - B. Recruitment
    1. Provider/Consumer Contact
    2. Agency Contact
    3. Church Bulletin
  - C. Community Education
- II. Provider Training
  - A. Workshop (groups)
  - B. One on One
  - C. In-Service
  - D. Applications
- III. Screening
  - A. Provider Home Visit
  - B. Letters of Reference
  - C. Determination of Acceptance of Provider
  - D. Certification of Provider Home

IV. Intake Process
   A. Referral
      1. Consumer
      2. Agency
      3. Other
   B. Client History
   C. Request
      1. Time and Place
      2. Persons to be cared for
V. Matching Consumer with Providers
   A. Consumer Needs with Provider Skills
   B. Consumer - Provider Meet
   C. Contract Negotiation
VI. Placement
   A. Fulfilling terms of Contract
VII. Follow-up
   A. Evaluation - Consumer/Provider
      1. Home Visit
      2. Telephone
      3. Written
   B. Documentation
      1. Logging
         a. General
         b. Individual

RESOURCES

To
the families with developmentally disabled members who were my teachers
and
to all the caring people who have been a major cohesive factor in our
respite care efforts

INTRODUCTION

RESPITE CARE: A LIFELINE FOR PARENTS OF THE DEVELOPMENTALLY DISABLED

Parents who have sons or daughters with developmental disabilities have been deeply hurt and desperately need healing of mind and spirit. The many perplexing questions and problems associated with developmental disabilities are overwhelming and bewildering.

In most families, the disabled child or adult places an extra burden of care on mothers and fathers. The unending responsibility for care, encouragement, training and daily life routines all falls to parents already carrying heavy burdens and often lacking the time, energy, and the propensity to set up support systems not easily accessible. With little relief from daily responsibilities, frustrations, feelings of isolation, physical and psychological exhaustion steadily mount.

Families with a disabled member need to feel they are not alone. The emergence of humanism and individual dignity as a way of life has led to an almost incredible awakening of the public conscience concerning developmental disabilities. Society has begun to appreciate and face its responsibility for the developmentally disabled person. It is now generally accepted that the resolution of the problems precipitated by the presence of a developmentally disabled person in the home is no longer the sole responsibility of the family or any single profession, discipline, or agency. It is one requiring the cooperative efforts and the pooling of knowledge, information, and resources of many, all directed to resolving the problem.

The intent of this manual is to provide a profile of a three-year old respite care service which will also serve as a "how to" model. It is written in the hope that other agencies interested in developing such services will not have to spend time on obstacles already overcome by this Project. The manual will also demonstrate how Church and State can work together to improve the quality of life for all.

We cannot hope to dispel pain for families with disabled offspring, even if that were desirable. This manual is written in hope of dispelling some of the loneliness and confusion by offering a credible model of family support.

In the end, we can hope that the pain of others can teach us to be compassionate and caring human beings. At least, presently, it is a deeply human condition in which we have been permitted to share.

Cary Carron
June, 1979

THE CHALLENGE

Previous efforts to provide respite care services by the five Associations for Retarded Citizens in the Denver Metropolitan area had met with little success.

In an attempt to serve families with a developmentally disabled member, three members of the Board of Directors of the Denver Association for Retarded Citizens met with the Director of the Ministry to the Handicapped of the Archdiocese of Denver in January, 1976. At this meeting the challenge was presented to the Archdiocesan Director to develop and implement a respite care service.

The challenge was overwhelming! The Archdiocesan Director asked for a week to consider the proposal before making a decision to accept or reject the challenge. Factors to be considered seriously before making a decision were:

1) the lack of success of previous attempts to develop respite services;
2) the Ministry to the Handicapped had not been a direct service provider;
3) funding for the respite care service was not possible from the Ministry to the Handicapped budget; and
4) the staff of the Ministry to the Handicapped was too small to provide direct services.

Factors having greater impact on the decision were:

1) the needs assessment by Denver Association for Retarded Citizens clearly revealed that respite care was a priority of parents (it ranked 4 on a priority list of 21);
2) respite care services would be a vital supportive service in keeping the family unit intact;
3) respite care service has a great potential to prevent the institutionalization of a disabled family member; and
4) a fact that we run into time and again is that every program is aimed at the developmentally disabled person because his/her need is so visible, while the families, who are also wounded, have no way to alleviate their needs.

PREPARATORY PHASE

Once the decision to accept the challenge was made, a new concept and approach had to be developed to avoid the pitfalls which had contributed to the lack of success of others who had attempted to provide respite care services.

Realizing that churches offer a vast, generally untapped, volunteer resource, the Archdiocesan Director was convinced that the success of this endeavor would be ensured if this compassionate, empathetic, and caring human resource were utilized. In February, 1976, to establish a sound base for respite services, the following strategies were employed:

1) the development of a working relationship with Denver Catholic Community Services, utilizing their expertise in the area of Foster Care as well as their contacts with the Social Concerns Committees in parishes. This resulted in the assignment of a full-time liaison staff member of Denver Catholic Community Services to work with the Archdiocesan Director;
2) the formation of a Steering Committee whose function was advisory and policy making. The Steering Committee was comprised of a representative from Denver Association for Retarded Citizens, Arapahoe Association for Retarded Citizens, Denver Catholic Community Services, and the Ministry to the Handicapped, as well as parents from two families with developmentally disabled offspring.
3) a series of meetings were held. Member agencies assumed the following responsibilities as groundwork for a pilot program:

    a. The Ministry to the Handicapped developed the pilot program.
    b. DARC and the Ministry to the Handicapped developed necessary forms to be used in the pilot program.
    c. DARC and the Ministry to the Handicapped developed the Orientation session for respite care providers.
    d. Denver Catholic Community services and parents developed the Screening forms used to evaluate the respite care provider homes.
    e. DARC and Ministry to the Handicapped, in conjunction with the Center for Legal Advocacy, developed contracts for respite care, researched licensing procedures of provider homes and investigated aspects of insurance and liability.

POLICIES

At the April 22, 1976 meeting, for following policies were set forth:

1) the Archdiocesan Director of the Ministry to the Handicapped will be the Respite Care Administrator and Coordinator (at least for the pilot program).
2) There shall be no Committees or Boards other than the Steering Committee. The Respite Care Administrator/Coordinator shall be responsible for the total program management.
3) For the pilot program, each Respite Care Home shall be limited to just one severely handicapped at a time.
4) The disabled individual needing Respite Care must live in the community with parents.
5) Respite Care must respond to emergency cases. Determination will be made by Respite Care Administrator/Coordinator.
6) Limit age to under 30 years.
7) Criteria for accepting requests from parents/legal guardians, and eventual placement shall be determined on the compatability of the provider and parents/legal guardians.
8) Orientation sessions and meetings involving Respite Care will be held at Archdiocese of Denver Ministry to the Handicapped Office, 2141 S. Zenobia Street.
9) All respite care providers shall carry insurance.
10) All Respite Homes shall be screened prior to using the home for respite services. The Screening Committee shall consist of a Masters in Social Work from Denver Catholic Community Services, Respite Care Administrator/Coordinator, and parents from two families with disabled members.
11) The Center for Legal Advocacy determined that a respite home need not be certified if the respite care placement is less than three consecutive days.
12) Each respite care provider shall have three letters of reference on file in the Ministry to the Handicapped office.
13) The Respite Care Administrator/Coordinator shall negotiate the service fee.
14) Fees for Respite Care Services shall be paid directly to the provider.

PILOT PROGRAM

RATIONALE:

Many parents of mentally retarded and other developmentally disabled children or adults are often faced with the problem of finding short term care, one to thirty days, maxiumum, for their sons or daughters. (For the pilot program short term care refers to no more than three consecutive days.) This short term care is needed for many reasons:

1) illness in family
2) doctor's appointment
3) to enable a family to take a vacation
4) to help a family cope with an emergency
5) simply for relief or "respite" from the often heavy demands of daily care.

For most families, the only viable choice is placement in an institutional setting. This is often difficult to accept as the handicapped person would be faced with the problem of adjusting to a setting that was much different from home. Forced into this solution makes it harder for parents to feel comfortable when they find placement necessary. Obviously there is a need for an alternative which would more closely approximate the warmth, familiarity, and structure which was part of the handicapped person's home. It is this need that we are attempting to meet in the development of a Denver Archdiocesan Respite Care Pilot Program.

PROCEDURE:

We see our preparatory work for the pilot program in this sequence:

1) identify Respite Families with the assistance of the Social Concerns committees of Notre Dame and St. Mary Parishes.
2) identify Families wanting Respite Service in conjunction with Denver Association for Retarded Citizens.
3) "Orientation" or educational series for Respite Parents is held This is designed according to the needs and interests of the Natural Parents.

4) When a request for Respite Service is received, the Respite Care Administrator/Coordinator arranges a visit into the home of the Natural Family in order to determine the handicapped persons's suitability for respite care. The Coordinator considers the handicapped person's needs and then matches the most appropriate Respite Family that will meet these needs.
5) a pre-placement visit is arranged with the Natural Parents, handicapped persons, Respite Family, and Coordinator at the respite home, affording the families an opportunity to become acquainted. During the pre-placement visit the dates of the respite service are finalized and the agreement for respite care is signed by the Natural and Respite Families.

SUPPORTIVE SERVICES:

The Respite Care Coordinator will be on 24 hour call should an emergency arise or should the Respite Family be in need of supportive services. The Administrator/Coordinator may be reached at business phone 936-7288 or at home phone 935-5059. Denver Catholic Community Services should be available to the Coordinator because supportive services must be an integral part of the program.

ON GOING EVALUATION:

After the actual visit, the Administrator/Coordinator contacts both families and records the Respite and Natural Parents assessments on the Placement Log. The Logs will be kept on file. An attempt will be made to utilize the same home if the Respite Service was successful.

MEDICAL RESPONSIBILITY:

The Natural Family assumes medical responsibility. The Archdiocese of Denver does not.

FEES:

The Natural Parents will be asked to pay the fee of $10 per day the first two days and $5 for each ensuing day. Hourly scale for less than overnight care will be $1 an hour.

Inability to pay the fee will not restrict the availability of this service. If the parents aren't able to pay, one of the three agencies, Denver Association for Retarded Citizens, Denver Catholic Community Services, or Ministry to the Handicapped shall subsidize the cost with monies available to Denver Association for Retarded Citizens, or from alternative sources of funding for Ministry to the Handicapped. We feel that it is necessary to charge a fee so that families will not consider this service to be a charity.

PLACEMENT INELIGIBILITY:

We generally will not place handicapped individuals who require one-to-one care or those with severe behaviorial problems, since this would require too much of the Respite Mother's time. We must avoid placing the Respite Mother in a situation where she might have to neglect her own family.

Also exempt from placement, at least for this pilot study, is the elderly retarded or disabled. This does not mean that if the pilot is successful we should not explore the possibility of doing something for those individuals over thirty years.

PROJECTED DATE:

June 15 is the projected date for the pilot program to begin. Should it become necessary to change this date, you will be apprized of the change.

Written and Presented by Respite Care Administrator/Coordinator

Approved by the Respite Care Steering Committee, April 22, 1976.

PROBLEM AREAS

Consumer Interest

During the summer months of 1976, response to the respite care program by parents of developmentally disabled persons was indeed disappointing. The program efforts met with many calls of inquiry but no requests for service. We interpreted this lack of response not as opposition to supporting respite care, but rather, as a reluctance to become involved in a program with which they were not too familiar.

In retrospect, this lack of response was probably due to three assumptions made by parents: 1) the respite service would be provided for only Catholic families, 2) the Archdiocese would probably proselytize the disabled person, 3) they would not get their hopes up for a service which had such a bad tract record and which again would probably be unsuccessful.

The Respite Care Pilot Program was launched, literally, in November, 1976, with the request from a social worker for emergency placement. Finally, with the documentation of this respite care placement, the program's credibility began to grow; indeed, it had escalated! Extensive use of the service was imminent.

SERVICE EXPANSION;

The publicity and popularity of the Respite Care Pilot Program had become wide spread. In addition to Denver and Arapahoe Associations for Retarded Citizens, Adams County, Aurora and Jefferson County Associations for Retarded Citizens became active members of the Respite Care team in January, 1978.

It was the consensus of this new Respite Care Team that the Archdiocese of Denver, because of its freedom to operate in all ARC counties in the immediate Denver Metropolitan Area, be the agency to provide the expanded service. Thus, the Archdiocese of Denver Respite Care Service, responding to the respite care needs of the Denver Metropolitan Area, was founded.

FUNDING:

With the rapidly increasing case load, other issues began to surface. Funding became the most critical issue. Directly related to funding was the need to employ a full-time person to coordinate respite services.

In an effort to generate more funding, the Archdiocese of Denver submitted a grant proposal to the Colorado Developmental Disabilities Council in February, 1977. The grant was awarded in June, 1977 for FY 1977-78.

Funding Facts:

Colorado Developmental Disabilities Council	$12,655.00
Cash Match (Five Denver-Metro ARC's Archdiocese of Denver)	4,385.00
	$17,040.00
Actual Budget FY 1977-78	$33,826.61

The grant afforded the following:

1) half salary for a full-time coordinator (the Archdiocese provided the remaining half);
2) operating expenses; and most importantly
3) financial assistance to help needy families to pay for the service.

It is important to note here that only on rare occasions was it necessary to subsidize the entire cost for the service. Almost every family using the service contributed something toward the cost, even if it were twenty-five cents per hour.

NATIONAL DEMONSTRATION MODEL

The Archdiocese of Denver Respite Care Project had gained recognition. In January, 1978, a representative of the Center for the Development of Community Alternative Support Services (CASS) visited the program. As a result of this on-site visit, the Project was chosen to be the National Demonstration Model for Community-Based Respite Services Systems.

With this distinction, the Project Director had the responsibility of conducting workshops for the First National Conference on Temporary Family Support Systems for Developmentally Disabled Persons held in Betheseda, Maryland, May 3-5, 1978.

It was gratifying that the Archdiocese of Denver Respite Service System brought added respect and recognition to the State of Colorado. Indeed, Colorado was accepted as the pioneer and leader in community-based respite services!

CHILD PLACEMENT AGENCY:

The wide-spread publicity and popularity of this Respite Care Project brought it under the scrutiny of the Colorado Department of Social Services.
After several meetings with members of the licensing department, it was decided that it would be necessary for the Ministry to the Handicapped office to purchase the services of a Masters of Social Work from Denver Catholic Community Services to become a Child Placement Agency. In February, 1978 the Archdiocese of Denver Ministry to the Handicapped office becamse a child placement agency.

CERTIFICATION OF RESPITE CARE HOMES

The issue of certifying all homes providing respite care became an issue in February, 1978.

Since its inception, it had been the practice of the Project staff to certify homes providing respite services for longer than three consecutive days, complying with the recommendation of the Center for Legal Advocacy.

Discussion and negotiation on the licensing problem has continued from February, 1978 to the present, August, 1979.

Central to the difference of opinions held in regard to certifying all respite homes is the determination made by the staff of the Social Services Division:

1. The Archdiocese of Denver, Ministry to the Handicapped is a licensed child placement agency and hold out to the parents of developmentally disabled children specific places which they have deemed appropriate for the care of those children on a short term basis. The issuance of the certificate will ascertain that indeed the home does meet the licensing requirements and the home is appropriate for the care of developmentally disabled children.

2. If at some future time that foster care is paid for through the County Department of Social Services, such homes will have to be licensed. It seems to be unequal treatment if a home were able to care for children without a license until such time as the fee for care came from a County Department of Social Services.

3. This State has no definition of occasional care of children in a family foster home. We believe it is improper to establish a definition for occasional care in a family foster home which cares for developmentally disabled children. Occasional care is defined in case law as irregular and infrequent care. The care described might be infrequent in that it is once a month, but it might be regular in that it is the fourth weekend of each month.

In response to Social Services stance, the Colorado Respite Care Consortium believes that respite care homes are not typical foster homes because parents maintain all their rights while the child is in respite care. To further support the Consortium's position, the parents/guardians approve the respite home as an appropriate setting before their son or daughter is placed. The Colorado Respite CAre Consortium will continue its efforts to resolve this issue with the Colorado Department of Social Services.

Cary Carron, Director
Respite Care Team
Archdiocese of Denver
2141 South Zenobia Street
Denver, CO 80219
(303) 936-7288

COLORADO RESPITE CARE CONSORTIUM

PHILOSOPHICAL POSTURE:

Respite Care represents a concern for the families with developmentally disabled persons living at home. These families are often the walking wounded, and a program which allows them occasional or periodic time off from the demands of caring for their handicapped person creates a much healthier atmosphere for the whole family, as it helps keep some light at the end of the tunnel for a parent who might otherwise feel that the world rests on their shoulders.

It is a fact that we run into time and again, that every program is aimed at the handicapped person, because his/her need is so visible, while the families, who are also wounded, have no way to alleviate their needs. We have found that a major benefit of respite care is to emphasize that it is serving primarily the family rather than the handicapped individual. This has tremendous psychological power to heal, (because it gives the family the right to be hurting and in need), and any healing in the family is a direct benefit to the developmentally disabled member of that family.

We sincerely ask your official support for respite care.

THE PROBLEM:

Families with developmentally disabled members have varied problems with which they must cope. There are times when the tensions become so great that it becomes necessary for the developmentally disabled individual to be temporarily out of the home. Due to a lack of alternatives, parents in crisis are often forced to initiate institutionalization for their son or daughter.

Until very recently the emphasis has been to provide service for developmentally disabled individual and not his family. It is this fact which has

precipitated the urgent and critical need for family support services, namely respite care.

ISSUES:

Tensions and crisis may develop from:

1) the extended hospitalization of a parent;

2) serious marital disharmony;

3) severe acting-out by the developmentally disabled member;

4) parents becoming overwhelmed with the care and responsibility of the developmentally disabled person; or

5) chronic health problems of the handicapped person, etc.

ALTERNATIVES:

An alternative way to respond to such crisis, ease the tensions in the home, better prepare the developmentally disabled individual to function at home or in the community, counsel families, and improve the quality of life for all is to provide respite services and counseling.

DEFINITION:

Respite Service is appropriate, short term temporary care, provided in a variety of settings, for the care of the developmentally disabled for a period of time, on a regular or intermittent basis to: (1) meet planned or emergency needs of the family and (2) restore and/or maintain harmony within the family unit.

This service is directed toward maintenance of the developmentally disabled person in his family home, although in some cases respite services could be utilized by other residential providers for similar reasons. Maximum stay per client shall be limited to no more than 45 accumulated days unless the need for a greater number of days can be documented.

LEVELS OF PRIORITY:

Three levels of need which would qualify a developmentally disabled person/ family for service are defined below.

1. A family unit may experience a need when it encounters an immediate personal or family crisis. The crisis will either already have occurred or be imminent, and unless assistance is made available, the family will suffer irreparable harm. The magnitude of such a crisis may be so great as to cause severe emotional, physical, and/or mental stress to members of the family.

Examples include: death of an immediate family member; divorce or severe marital problems within a family; hospitalization or serious illness of a family member (one largely responsible for the care of the developmentally disabled person); severe emotional physical, or mental family stress; the birth of a baby; or temporary loss of residential placement for a developmentally disabled individual.

2. Another need is considered to be more preventive in that stress relief might decrease the chance of amore serious crisis in the future. During the period of stress, the presence of the developmentally disabled person in the home may magnify the problem the family is facing and, if not checked, might lead to a greater problem in the future. In such instances, the best course may be to remove the developmentally disabled person from the family environment until the family's problems have been resolved.

In allowing the family an interim period of relief, the problems that first caused placement may sometimes be alleviated. For example, the techniques that family relief provider may use in dealing with a developmentally disabled person's behavior problems or lack of skills can be shared with the family prior to the individual's return home.

Examples of these types of crisis may include: the death of a close friend or relative; a business trip which takes the supportive member away from the home; a family move in which the developmentally disabled individual is not be involved until the move is completed; family stress; problems with other children in the family; or, temporary loss of a "babysitter".

3. A family makes many sacrifices to meet those special needs of a developmentally disabled individual who requires virtually constant attention. If there is actual or anticipated difficulty in securing relief, parents may sacrifice their social lives, feeling compelled to meet all the needs of the developmentally disabled person. The resulting tension may not allow for approximate attention to the needs of other family members. Examples would include a much-needed vacation, time off, or non-residential supervision for part of a day or evening.

TARGET POPULATION (STATE WIDE):

Respite services will be provided for developmentally disabled persons with any age limitations.

PROJECTED CONSUMERS TOTAL NEEDS (STATE):

Needs

1) Short Term Temporary care

2) Counseling

3) In-home support

Existing Resources to meet the needs:

Respite Services Projects:

1. Denver Archdiocese - National Demonstration Model
2. Mesa County ARC
3. Pueblo ARC
   a. Respite service
   b. Counseling
   c. In-Home support

Cannot identify any other community-based resources

FAMILY RESOURCE SERVICES

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS

AGENCY SURVEY

JANUARY, 1980

Date: January 21, 1980 Interviewer: Cary Carron

Name of Agency: Archdiocese of Denver Ministry to the Handicapped

Street: 2141 South Zenobia Street

City: Denver State: Colorado Zip: 80219

Program Contact: Gary Haug

Title: Respite Care Coordinator Telephone: (303) 936-7288

Applied Definition for Family Resource Services Respite service is appropriate, short term temporary care, provided in a variety of settings, for the care of developmentally disabled for a period of time on a regular or intermittent basis to: 1) meet planned or emergency needs of the family and 2) restore and/or maintain harmony within the family unit.

Part A: Demographics of Agency which is Sponsoring/Governing the Family Resource Services

1.0 Population served by entire agency

1.1 Geographic area (e.g., state, counties, # people, rural or urban) 4 counties making up the Denver metropolitan area

22

1.2 Total population agency serves (e.g., general populace; special segment) developmentally disabled people

1.3 Age range of persons served no age limit

1.4 Disabilities of persons served (primary, secondary and other) children and adults who are mentally and physically disabled.

23

1.5 Percentage of persons served who are diagnosed as severe/profoundly handicapped and/or multi-handicapped 15%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority?

1.6 Percentage of those who require more than average (of population served) amount of training/care 17%

1.7 Percentage none-ambulatory 26%

2.0 Types of service offered through agency Respite Care in and out of home follow-up counseling, family and community education

3.0 Sources of referral to agency public and private agencies, private physicians, psychologists, schools, associations for retarded citizens (ARC's)

4.0 Governing/decision-making mechanisms

4.1 Persons/boards/committees Cary Carron, 5 ARC Executive Directors

4.2 State and local regulations, guidelines, standards, zoning Division for Developmental Disabilities and Colorado Department of Social Services

4.3 Current, pending, and future legislation Funding

5.0 Funding sources (percentage if known)

5.1 Federal

5.2 State X

5.3 Local

5.4 Other X Archdiocese of Denver (Private) ARC's

6.0 Agency's strengths/areas of excellence (Explain/Describe) The simplicity of administration allows for creative and flexible responses to individualized needs of clients and families. The credibility of the Director and agency enhances continuity and quality of services. Good working relationship with community Resource people.

7.0 Agency's limitations/ areas requiring improvement Lack of funds to expand services.

Part B. Family Resource Services/Program

1.0 Program Abstract (Please include any formal literature about the Family Resource Services program.)

Description and Components of Family Resource Services Program

1.1 Historical Perspective (how, and when program was started) Need for respite care was identified by the Denver Association for Retarded Citizens. At their request, Cary Carron, Director of the Ministry to the Handicapped, Archdiocese of Denver, started the respite care program in January, 1976, using trained private homes in the community to provide respite care.

1.2 Where services are provided

A. In-home X

B. Out-of-home X

C. Institutional setting

D. Other

1.3 Means of delivery Individualized

2.0 Population served through Family Resource Services (note: percentages may overlap)

2.1 Total number served FY1978-79 served 310

2.2 Age range No limit

2.3 Disabilities of person served All developmental disabilities

2.4 Percentage age:

A. 0 - 5 33%

B. 5 - 18 49.5%

C. 19 - 29 9%

D. 30 - 55 6.5%

E. 55 and over 2%

2.5 Percentage of severe/profound (multi-handicapped) 15%

What is the definition of severe/profoundly handicapped and/or multi-handicapped used by your agency, funding source or other authority? We use AAMD definitions

2.6 Persons who need intensive or specialized training/care 65%

Explain what is meant by those "who need intensive or specialized training/care" Medically fragile persons or those with developmental and/or behavioral problems.

2.7 Percentage non-ambulatory 26%

3.0 Recruitment of Family Resource Services Program staff

3.1 Target group Interested caring people in the community. (We do the training.)

3.2 Method Church Bulletins, media resources, word of mouth, recommendation

3.3 Recruitment materials, tools used/developed Word of mouth, church bulletin, personal contact

4.0 Training of Family Resource Services

4.1 Target group Respite care providers

4.2 Method Training sessions and in-service provided by families.

4.3 Curriculum Basic understanding developmental disabilities, Medical/nursing aspects, legal aspects, parents' panels.

4.4 Training materials; tools used/ developed Training manual, visual aids, actual clients.

4.5 Source of funding Respite Care Budget

5.0 Community Development

5.1 Media resources ARC Newsletters, Church Bulletins, P.S.A. radio and television

5.2 Parent education Each training session and as needed

5.3 Agency education Continuing education, seminars, workshops, and active participation on private and public agency committees.

5.4 Community education Presentation of workshops, lectures and films.

5.5 Materials; tools used/ developed see 5.1

6.0 Administration

6.1 Criteria for eligibility of Family Resource Services Clients live in the Denver Metropolitan Area and diagnosed as developmentally disabled.

6.2 Duration of services (maximum, minimum, and average amounts of time) service is provided Duration is from an hour to 30 consecutive days unless there are extenuating circumstances.

6.3 Methods of referral to program Telephone or direct contact with Respite Care staff.

6.4 Method of referral to service providers Same

6.5 Cost of service to client/fees charged by agency/sliding scale $1 an hour or $10/day. More involved cases negotiable. - sliding scale.

6.6 Cost of service to agency (operating, indirect, capital costs) N/A - Program cost $36,000 FY 1978-79

6.7 System of payment (broker, voucher, direct, to service provider, etc.) Consumer pays provider directly - supplemental assistance by Archdiocese/voucher.

6.8 Provisions for transportation None (consumer responsibility)

7.0 Governing/decision-making mechanisms

7.1 Persons/boards/committees Two - Respite Care Director and Coordinator

7.2 State and local regulations, standards, guidelines, zoning Agency had become a Child Placement Agency and homes providing 72 hours Respite Care in any one week must be certified - Colorado State Department of Social Services.

7.3 Current, pending, and future legislation Colorado Legislatures Joint-Budget Committee for Continuation of State funding.

8.0 Family Resource Services staff/personnel

8.1 Total number staff 2

8.2a Number supervisory staff/administrator 1

8.2b Professional expertise, special training or skills, relevant experience, etc. Director has a Masters degree in nursing, Post-graduate education Special Education and 20 years of experience in field.

8.3a Number direct service staff 102

8.3b Professional expertise, special training or skills, relevant experience, etc. see 4.3 and experience.

8.4a Number ancillary/secondary support staff (e.g. OT, P.T., etc.) Unlimited

8.4b Professional expertise, special training or skills, relevant experience, etc. Professionals in all areas.

8.5 Staffing patterns/system for scheduling direct services staff N/A

9.0 Funding sources

9.1 Government funding

A. Federal (specify contract, grant, hard money, etc)

B. State X

C. Local X

9.2 Client direct payment Yes

9.3 Donations None

9.4 Other ARC's

10.0 Available Family Resource Services Resources for Program Planning, Service Delivery, etc.

10.1 Persons (parents, professionals, etc.) J.F.K. Child Development Center

10.2 Agencies (supportive, ancillary, generic) Public Schools, ARC's, Community Center Boards

10.3 Materials/Tools IHP and IPP - pre and post respite care

11.0 Needed Family Resource Services

11.1 Persons (parents, professionals, etc.) Providers

11.2 Agencies (supportive, ancillary, generic)

11.3 Materials/Tools

12.0 Strengths/strong points of Family Resource Services program Excellent care givers - community based; keeps family unit intact, good personal relationship with comsumers and providers.

13.0 Identified weaknesses/limitations of Family Resource Services Expansion - especially funding and staff

14.0 Evaluation/Accountability

14.1 Internal Client records - follow up

14.2 External Consumer/provider evaluation of services

15.0 General Comments

16.0 Names and addresses of other programs and agencies providing this service that you are aware of and would recommend, etc.,